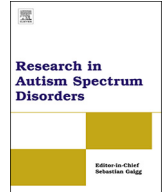


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# Research in Autism Spectrum Disorders

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## Positive and negative cognitive appraisal of the impact of children with autism spectrum disorder on the family

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### ABSTRACT

**Background:** This paper investigates the measurement of cognitive appraisal in the context of childhood disability in a middle-income country, and describes how South African families positively and negatively appraise the impact on the family of raising a child with autism spectrum disorder (ASD).

**Method:** We used the responses of 180 parents who completed the *Family Impact of Childhood Disability (FICD) Scale*, which was part of the survey data gathered in a larger study that examined the perspectives of families of young children with ASD in South Africa. Participating families were recruited from 35 disability-related service providers in the Gauteng province.

**Results:** Our findings provided preliminary evidence about the suitability of using the *FICD* Scale in the South African context. The results indicate that the participating families perceived the impact of their child with ASD as both positive *and* negative.

**Conclusions:** The results of this study supported the universal properties of positive *and* negative appraisal when raising a child with a disability. Like other families in other countries, the participating families perceived the impact of a child with ASD as both positive *and* negative and revealed that parents are able to re-create positive meanings about the impact of their child diagnosed with ASD.

### 1. Introduction

There is a large body of evidence that confirms that children with autism spectrum disorder (ASD) pose a range of distinct challenges to families, that parents and siblings experience high levels of stress, and that life is hard for these families. While the body of evidence of the positive impacts of raising a child with ASD is slowly growing (e.g., Bayat, 2007; Hastings, & Taunt, 2002; Little, & Clark, 2006; McConnell, Savage, Sobsey, & Uditsky, 2015), there is a risk that the dominant portrayal of a negative impact elicits an elaborate representation of the challenges associated with ASD (Gardiner & Iarocci, 2012; Hastings, 2016; Karst & Van Hecke, 2012). Although researchers are yet to understand the full range of families' experiences when raising a child with ASD, stress and coping theory and research have shown that families can perceive (or cognitively appraise) the impact of their child with a disability as both negative *and* positive (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986; Larson, 1998; Trute & Hiebert-Murphy, 2002; Trute, Hiebert-Murphy, & Levine, 2007). For example, a family can think that their child with ASD has led to limitations in social contacts outside their family home – a cognitive appraisal that is negative; simultaneously, yet independently, they can also think that their child makes life more meaningful for them – a cognitive appraisal that is positive.

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Much of what we know about the positive and negative appraisal of raising a child with ASD comes from high-income countries (e.g., Bayat, 2007; Fong, 1991; Little & Clark, 2006; Myers, Mackintosh, & Goin-Kochel, 2009; Paynter, Riley, Beamish, Davies, & Milford, 2013; Phelps, McCammon, Wuensch, & Golden, 2009; Sim, Cordier, Vaz, & Falkmer, 2016), thus favouring the perspectives of families in those countries. Research indicated that positive and negative appraisal play an essential role in coping and family functioning for families raising children with ASD and other disabilities (Costa, Steffgen, & Ferring, 2017; Myers et al., 2009). The associations between positive and negative cognitive appraisal and family functioning vary, but overall the findings of these studies support the theory that positive appraisals relate to more positive outcomes and that greater negative appraisals relate to greater negative outcomes. For example, positive appraisals have been associated with better relationship quality (Paynter et al., 2013; Stuart & McGrew, 2009), and better family adjustment (Neely-Barnes & Dia, 2008). Negative appraisals have been associated with higher levels of psychological distress in the family system, higher parenting stress, and a negative impact on the family (Paynter et al., 2013; Stuart & McGrew, 2009).

Extremely little is known about the perspectives of families raising children with autism in sub-Saharan Africa, including South Africa. Franz, Chambers, Von Isenburg, and De Vries (2017) conducted a scoping review of published ASD research up to 2015 in sub-Saharan Africa. The authors identified only seven studies that investigated the family perspectives of South African families on ASD. Based on the quantitative and qualitative data gathered from these studies, many families reported the negative impacts of having a child with ASD. Examples were the financial strain of raising a child with ASD; the isolation that the family experience; and the stigma of having a child with a disability (Fewster & Gurayah, 2015; Mitchell & Holdt, 2014). In contrast, one of the studies identified characteristics and resources that helped South African families to adapt and be resilient (Greeff & Van der Walt, 2010). Families reported that maintaining a positive outlook and remaining hopeful were among the factors that helped them to adapt to having a child with ASD.

Context is particularly important when we consider the construct of cognitive appraisal. How families define the impact of their child with disability reflects to some degree the larger context of societal attitudes and historical realities within which that interpretation emerges (Ravindran & Myers, 2011; Silverman, 2008). Skinner and Weisner (2007) talk about how “families may create their own personal understandings of disability of the child who is affected, but these understandings are not private” (p. 303), and that families’ appraisals are shaped by, or sometimes forged in opposition to, different cultural models and definitions of disability that families encounter in different communities. Researchers have to conduct a great deal more research in low- and middle-income countries to establish the measurement of universal family concepts such as positive and negative appraisal; to test the generalisability of existing family research findings; and to investigate how multicultural families in different contexts adapt to raising a child with ASD (Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004; Hastings, 2016).

Therefore, the focus of the current paper is to describe South African families’ positive and negative cognitive appraisal of the impact of children with ASD on their families. Additionally, because this study is the first in the South African context to measure this concept in this study population, attention is given to the psychometric properties of the selected measurement instrument. Of interest to the international audience, this paper addresses a call to apply a balanced approach (considering negative *and* positive perspectives) when conducting research on families raising children with ASD (Hastings, 2016), and explores how a sample of South African families cognitively appraise the impact of raising a child with ASD. Locally, it contributes to the much-needed autism research, particularly investigating family perspectives of ASD.

## 2. Methods

### 2.1. Sampling and procedure

Ethics approval for the study was obtained from the Research Committee of the University of Pretoria and the Gauteng Department of Education. The data for this study was obtained from a larger research project that investigated the family perspectives of families raising a young child with ASD in Gauteng (Schlebusch, Samuels & Dada, 2016; Schlebusch, Dada, & Samuels, 2017). Non-probability, purposive sampling methods were used to recruit participants. A primary caregiver who was English literate acted as a proxy for families. A family could participate in the research study if: (a) they had a child younger than nine years old, who was (b) diagnosed with ASD, and (c) attended disability-related schooling or intervention services in the Gauteng province of South Africa. The diagnosis of the child with ASD was based on parental report. This method was preferred because of the difficulties (and often long waiting periods) for some families to get an official diagnosis of ASD for their child, although their child is already attending a school or organisation for children with ASD. To control for potential sampling error, various structures was put in place, namely (a) organisations that specifically offer services for children with ASD was contacted to assist with the recruitment of participants and (b) these organisations identified the children with ASD attending their school and only delivered a survey packet to the identified families. Gauteng accommodates 29% of all households in South Africa; 20% of South Africa’s children; it is the province with the lowest rate of child poverty (35%); and children have the highest rates of access to health services (Hall & Sambu, 2017). Public and private organisations (n = 35), located in all five municipal districts of Gauteng in a variety of urban and suburban areas serving different communities, helped to identify 380 potential families. Each family received an envelope containing a survey booklet and information letter. The information letter explained the aims of the study and stated that participation was voluntary, that the family’s information would be kept confidential and that they would not be identified in any manner. The parent or primary caregiver was asked to complete the survey on behalf of the family. Informed consent was obtained from all participants included in the study. Upon completion, the survey was returned to the organisation in a sealed envelope. A total of 180 families completed and returned the questionnaire, resulting in a 47% return rate.

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